



BILLING CODE: 4165-15

**DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**Health Resources and Services Administration**

**Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Service Administration (HRSA), Department of Health and Human Services.

**ACTION:** Notice of meeting.

**SUMMARY:** In accordance with section 10(a)(2) of the Federal Advisory Committee Act (Public Law 92-463, codified at 5 U.S.C. App.), notice is hereby given that a meeting is scheduled for the Advisory Committee on Heritable Disorders in Newborns and Children. This meeting will be open to the public but advance registration is required to ensure sufficient webinar capacity. The registration link is <https://www.blsmeetings.net/achdncnovember2016/>. The registration deadline is Wednesday, November 2, 2016 11:59 PM Eastern Time.

**DATES AND TIMES:** November 3, 2016, 9:00 a.m. to 5:00 p.m. (Meeting time is tentative.)  
November 4, 2016, 9:00 a.m. to 1:00 p.m. (Meeting time is tentative.)

**ADDRESS:** This meeting will be held by webinar only.

**FOR FURTHER INFORMATION CONTACT:** Anyone interested in obtaining other relevant information should contact Alaina Harris, Maternal and Child Health Bureau, HRSA, Room 18W66, 5600 Fishers Lane, Rockville, Maryland 20857; email: aharris@hrsa.gov.

**SUPPLEMENTAL INFORMATION:** The Advisory Committee on Heritable Disorders in Newborns and Children (Committee), as authorized by the Public Health Service Act, Title XI, § 1111 (42 U.S.C. 300b-10), was established to advise the Secretary of the Department of Health and Human Services about the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. In addition, the Committee's recommendations regarding additional conditions/inherited disorders for screening that have been adopted by the Secretary are included in the Recommended Uniform Screening Panel and constitute part of the comprehensive guidelines supported by HRSA. Pursuant to section 2713 of the Public Health Service Act, codified at 42 U.S.C. 300gg-13, non-grandfathered health plans are required to cover screenings included in the HRSA-supported comprehensive guidelines without charging a co-payment, co-insurance, or deductible for plan years (i.e., policy years) beginning on or after the date that is 1-year from the Secretary's adoption of the condition for screening.

The Committee will hear presentations and discussions on topics related to newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. The Committee will also hear updates from the Laboratory Standards and Procedures workgroup, Follow-up and Treatment workgroup, and Education and Training workgroup. Agenda items are subject to

changes as priorities indicate. Tentatively, the Committee is expected to review and/or vote on the following: approving newborn screening surveillance case definitions and whether or not the nominated condition Guanidinoacetate Methyltransferase deficiency should be referred for a full evidence-based review. The Committee will not be voting on a proposed addition of a condition to the Recommended Uniform Screening Panel. The meeting agenda will be available 2 days prior to the meeting on the Committee's website:

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Members of the public may submit written and/or present oral comments at the meeting. All comments are part of the official Committee record. Advance registration is required to submit written comments and/or present oral comments. Written comments must be submitted by October 19, 2016 11:59 PM Eastern Time in order to be included in the November meeting briefing book. Written comments should identify the individual's name, address, email, telephone number, professional or business affiliation, type of expertise (i.e., parent, researcher, clinician, public health, etc.), and the topic/subject matter of comments.

Individuals who wish to provide oral comments must register by October 30, 2016, 11:59 PM Eastern Time. To ensure that all individuals who have registered to make oral comments can be accommodated, the allocated time may be limited. Individuals who are associated with groups or have similar interests may be requested to combine their comments and present them through a single representative. No audiovisual presentations are permitted.

More information on the Advisory Committee is available at

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Jason E. Bennett,

Director, Division of the Executive Secretariat.

[FR Doc. 2016-24808 Filed: 10/13/2016 8:45 am; Publication Date: 10/14/2016]